

Accessing Funding Through State and Federal Programs

Caring for children with autism can be overwhelming. There are so many needs and life is often chaotic, especially when severe behaviors are involved. I have met many parents who were desperate for help and support, yet were too overwhelmed with day-to-day life to be able to figure out their child's rights and their right for support.

There are roughly three avenues of support for our children, and it is our role as parents to advocate these three avenues tirelessly in order for our children to receive the maximum help.

The first avenue is the school program. Different states and different towns and school districts offer different services, but under federal law, services should be based on a student's individualized needs. Unfortunately, the services offered are often dictated by the town's budget rather than the child's needs. That's when we parents come in and advocate. The difference that getting involved and advocating can do in getting your child the right program is vast. Do not hesitate to ask around in your community, talk to other parents, collect the most information, and use a professional when needed. It is usually worth the initial investment because your child has many years in school. You may need more help along the road, yet the initial creation of a good program is very important.



This section was prepared by Shirley Blaier-Stein, the author of *Autism Mom: New Ways of Thinking*, an attorney and an autism advocate. Shirley's son has autism. He attends a behavior-focused school in CT and is doing well. Shirley lives and writes autism and is passionate about helping autism parents reach their potential in order to become empowered, exercise their children's rights, achieve the best program and treatment for their children, and help their children thrive.

The second avenue for services is health-related therapies covered by health insurance. Services such as speech therapy and occupational therapy are typically covered. In recent years, some states have adopted laws that mandate covering behavioral therapy for children with autism. Such therapy is need-based and must be assessed by a medical professional. Once your child gets approved, he/she will receive hours of therapy that typically help tremendously.

The third avenue and the one I will focus on here is government entitlements like Medicaid.

Medicaid Funding

What is Medicaid?

Medicaid is a program that is funded in part by both the federal and state government. Medicaid pays for a wide array of services for people with disabilities and provides government-funded health insurance for children and adults with disabilities who have limited financial resources. Medicaid also provides government funding for long-term services and supports. An individual can qualify for Medicaid based on both income and disability. Eligibility rules vary across states.

Determining Eligibility and Application Process

To be eligible for Medicaid, an individual must meet financial eligibility criteria which looks at the individual's (or in the case of a child, their parents') income and resources. Income and resource limits vary within and across states. Eligibility is also determined based on an individual's functional level-of-need, i.e. the healthcare and support needs created by the individual's disability. Functional eligibility also varies within and across states both in terms of the criteria and levels set as well as the processes by which states determine eligibility. Eligibility criteria vary widely and states have many optional rules that they can use in determining eligibility.

As a result, parents and individuals should consult experts in their state's Medicaid program, such as the state protection and advocacy system for individuals with developmental disabilities, to learn more about the specific rules in their state. That being said, in all but 10 states, if an individual is eligible for Supplemental Security Income (covered later in this section), he or she automatically qualifies for Medicaid.

To obtain Medicaid, you must apply through the relevant agency in your state (such as Department of Health or Department of Developmental Services, depending on where you reside). Such requests need to be supported by medical documentation showing a child's current medical status needs. An academic evaluation and diagnosis would not do for that purpose.



Home and Community Based Services (“the Waiver”)

In the past, Medicaid funding was limited to those who live in certain types of facilities. But now, through the use of **Medicaid Home and Community-Based Services (HCBS) Waivers**, people with autism and other disabilities can use these funds more flexibly. The program enables states to serve people who wouldn't normally be eligible for Medicaid or provide services that aren't offered as part of the regular Medicaid benefit package in that state.

The purpose of HCBS waivers is to provide services that offer an alternative to Medicaid institutional services such as intermediate care facilities, in-patient psychiatric facilities or nursing facilities. HCBS waiver services may, for example, provide support to families and individuals to help them remain in the home and community. In many cases, HCBS programs enable state Medicaid programs to achieve greater cost effectiveness within their long-term care programs.

States have considerable flexibility in designing their HCBS waiver programs. Eligibility levels (both financial and functional), services and benefits available (in terms of type, amount, duration and scope) and populations served vary across HCBS programs within and across states.



Services Covered

Services covered under the waiver include support in the home and in the community. There are many different services available in HCBS waivers and the exact type, amount, duration and scope of services available is determined by the state.

Therefore, you should contact the state agency that operates the waiver to find out which services are available. Waiver services can include things like in-home behavioral support, in-home support staff, care coordinator (case manager), respite, and others. Such services are different from the typical Medicaid services provided outside of the waiver.

States also allow Medicaid participants to self-direct their care, meaning the participant gets a budget and can hire and manage staff independently. This allows more flexibility and control of who is working with the participant. Insurance services are often not self-directed and follow the medical model, meaning an agency or medical professional is hired to run the program, and brings their own staff to support the individual. Typically this leads to better supervision of staff and therefore more accountability.

The level of support varies from state to state and depends on the level of care and necessity for the individual.

State Department of Developmental Disabilities

Another source of funding is your state's agency supporting individuals with **developmental disabilities (DD)**. (The names vary across states – in some states it's a department, others a division, etc.)

There is wide variation across states in terms of the services available through the state's DD agency. In some states, the services received through Medicaid and HCBS waivers will actually be provided by your state's DD agency. (In these cases, the Medicaid agency provides the funding for the programs that serve individuals with developmental disabilities, but contracts the DD agency to actually provide the services.) Some DD agencies might also provide services beyond what is available through Medicaid, including respite care and supported employment services, among others. Be sure to check with your state to see what services are offered by the DD agency and which supports your family is eligible for.

The pathway to eligibility and to access those services isn't always straight or clear. In fact, it is often quite messy. So it is important to do your homework! Make sure that you are contacting both Medicaid and the DD agency in your state to be certain that your child is getting everything to which he or she is entitled. And don't be afraid to be persistent! Many of these available services can be very helpful to your entire family.

You can learn about and find the contact information for the agency in your state on the [National Association of State Directors of Developmental Disabilities Services \(NASDDDS\)](#) website.

I always associated Medicaid with health insurance coverage for the financially disadvantaged and assumed that was it. Now I know there is so much more to it. And I'm so glad I do!

Funding from the Social Security Agency

A very important funding channel for your child's future is through the U.S. Social Security Administration (SSA). This funding can come in two different ways: Supplemental Security Income and Social Security Disability Insurance.

Below is a brief overview of these two benefits and some information on how you can access them for your family if not eligible.

Supplemental Security Income

Supplemental Security Income (SSI) is a Social Security program that makes monthly payments to adults and children who have limited income and resources and meet Social Security's definition of disability. For low income families, monthly SSI payments can be very helpful to cover expenses.

Definition of Disability

To be considered disabled and eligible for SSI, your child must meet all of the following requirements:

The child must not be working and earning more than \$1,090 a month in 2015. (This earnings amount usually changes every year.)

The child must have a physical or mental condition, or a combination of conditions, that result in "marked and severe functional limitations." This means that the condition(s) must very seriously limit your child's activities.

The child's condition(s) must have been disabling, or be expected to be disabling, for at least 12 months or the condition(s) must be expected to result in death.



Limited Income and Resources

To determine whether your child is eligible to receive these monthly payments, the SSA will consider the income and resources of all family members living in the child's household, including the child if he or she is working. The minimum earnings amount usually changes every year. The test for eligibility takes into account an individual's income as well as resources. Income means money earned from work; money received from other sources, such as Social Security benefits, or even friends or relatives; AND free food and shelter. For example, when the child lives with his family, the shelter and food he receives from his family counts towards "income."

Resources means cash, bank accounts, stocks, U.S. savings bonds, land, vehicles, personal property, life insurance and anything else you own that could be converted to cash and used for food or shelter. Liquid resources must be under \$2,000.

The SSA will look at the household income and assets and the parental living allowance to determine how much a child will receive in SSI benefits.



Applying for Disability Benefits

There are two ways that one can apply for disability benefits:

1. Apply online at [SocialSecurity.Gov](https://www.socialsecurity.gov); or

2. Call 1-800-772-1213, to make an appointment to file a disability claim at the local Social Security office or to set up an appointment for someone to take the claim over the telephone.

When you apply for SSI payments, you will also need to fill out a [Child Disability Report](#) on behalf of your child. In addition to requesting your financial documents, the SSA will ask you for lots of detailed medical information about your child's condition and how it affects his or her functioning level. You may need to give permission to his or her doctors, teachers, therapists and other professionals to share information with the SSA. The more information you provide, the easier the process will be. They may require your child to take additional tests or assessments, all at their own expense. It can take 3 to 5 months to decide a child's SSI disability claim.

Based on the information you provide, the SSA will determine a dollar amount for monthly benefits. Once your child starts receiving SSI, the SSA will review his or her condition from time to time to be sure that he or she still meets the criteria for eligibility. The review happens at least every three years.

When Your Child Turns 18

When a child becomes an adult at age 18, the SSA uses different rules to determine if he or she is eligible for SSI disability payments and as a result, you will need to go through a redetermination process to maintain his or her benefits as an adult. At age 18, only the individual's income and resources are counted when determining eligibility for SSI. As a result, there are many individuals with disabilities from higher income families who do not qualify for SSI until they turn 18.

There are also different rules when deciding whether an adult is disabled. The SSA will review your child's condition when he or she turns 18. As an adult, "disability" under Social Security is based on an individual's inability to work.

If your child is 18 or over and working or interested in working, his or her Social Security benefits do not have to be disrupted. The SSA offers some work incentives in order to allow individuals receiving SSI to work and keep their benefits. These include a **Plan for Achieving Self Support (PASS)**, **Impairment-Related Work Expense (IRWE)** and the **Ticket to Work** program.

You can learn more about these rights in the Autism Speaks Employment Tool Kit. Call the [Ticket to Work Help Line](#) to speak to an expert about your child's specific situation at [866-968-7842](tel:866-968-7842) or visit [ChooseWork.net](https://www.choosework.net).

Social Security Disability Insurance (SSDI)

Social Security Disability Insurance provides income supplements to people who are restricted in their ability to be employed because of a disability. The SSDI program pays benefits to adults who have a disability that began before they became adults. SSDI is payable to adult “children” of parents who are receiving Social Security retirement or disability benefits; or who have died and worked enough prior to their deaths to qualify for Social Security benefits. The SSA considers this a “child’s” benefit because it is paid on a parent’s Social Security earnings record. These benefits continue as long as your child meets the definition of disabled.

One important difference between the two programs is that SSDI payments are uniform in all states. SSI is different in each state, as sometimes the state supplements the federal payments.

Summary of Social Security Benefits

In summary, if your child is considered disabled by the SSA’s definition (which is different for children and adults), SSI payments are an option if:

Your child is under the age of 18 and your household meets a limited income and resource requirement; or

Your child is age 18 and over and his or her income meets a limited income requirement (your income and resources are not counted when determining eligibility)

In addition, SSDI payments are an option if:

You or your spouse receive Social Security benefits; or

You or your spouse pass on after paying Social Security taxes



SSI and Medicaid benefits for my son have been even more helpful than I thought they could be. Because of SSI, he was able to start working using the PASS work incentive program. Through Medicaid, he has been able to keep up with regular doctor appointments and transportation has been provided to and from the appointments. It took some serious advocating to make sure he got those benefits he deserves, but it was certainly worth every ounce of hard work!

Other Entitlements

Once you or your child are eligible for payments through SSI, you may also be able to access additional supports. In all but 10 states, if you are eligible for SSI, you are automatically eligible for Medicaid. In many cases, eligibility for SSI also automatically qualifies you for other low-income assistance programs in your state. These can include, but are not limited to:

[Supplemental Nutrition Assistance Program](#) (SNAP), also known as food stamps

Energy cost savings through the [Low Income Home Energy Assistance Program](#) (LIHEAP)

[Childcare subsidies](#)

[Temporary Assistance for Needy Families](#) (TANF)

[Head Start](#) (school readiness programs for young children)

Housing assistance (Contact your [local public housing authority](#) - often low-income housing will prioritize services for individuals who are disabled or are receiving SSI.)

Transit subsidies (Contact your [local public transit authority](#) - transit authorities will discount or offer special fares to people who are disabled.)

[Work Incentives Planning and Assistance](#) (service to help you plan benefits in way that enables you to work)

Keep in mind that many of these entitlements are state-specific so you will have to reach out directly to your specific state office.

The most important thing when securing these benefits is to be persistent. Oftentimes the SSA might exclude people with autism with higher functioning levels from the definition of “disabled.” You may need to appeal the SSA’s decision if your family is denied benefits to which you are entitled based on your child’s diagnosis or if you feel your benefit amount should be higher. There are four levels of appeal: reconsideration, administrative law judge hearing, appeals council review and federal court. Benefits from the Social Security Administration can be very helpful for families in the autism community. Don’t give up!

